## Keynote Address Presented to the First Regional Seminar On Home Care for Ventilator-Dependent Children & Adults St. Louis, Missouri December 13, 1983

There appears in this archive the keynote at the first ever Surgeon General's Workshop under my aegis, which was on the subject of Ventilator-Dependent Children. This was a seminal meeting, because it was my belief that if we could manage the care of ventilator-dependent children at home, we could manage the care of any kind of handicapping situation at home.

It was the beginning of a number of things that I continued to track through my eight-year tenure as Surgeon General, and the goal can be stated briefly as an effort to provide for all "Special Needs" children comprehensive, coordinated, family-centered, community-based care.

The history of this movement while I was Surgeon General is an example of how well something can be done by government when the right people are involved, and when the subject catches on. A tremendous amount of credit goes to Vince Hutchins, the Director of the Bureau of Maternal and Child Health in the Public Health Service, and to his associate, Merle MacPherson. They worked tirelessly with me until the aforementioned goal was eventually incorporated into "Title V" of the Social Security Act as a guarantee to every "Special Needs" child in this country.

The original Surgeon General's Workshop was followed by regional workshops, state workshops, and community workshops all over the country. Just a catalog of the meetings that were held and brief summaries of their accomplishments filled a book. This keynote, by me, was addressed to the first of the regional workshops we had on this subject and was followed by many throughout the country, in all of which I was not able to participate.

One of the frequent questions I'm asked is, "What was my greatest accomplishment in Washington during my term as Surgeon General"? I answer it in many ways, and of course, it depends upon who asks the question and what their interest is. However, I think in the long run the number of lives that were affected by the work that was begun at the first Surgeon General's Workshop on ventilator-dependent children resulting in the change in the Social Security Law Title V, may well in the long-run be one of the most important things in which I became engaged.

Definition of the problem
Discrimination
Financing of care
Identifying areas of potential abuse
Incorporating principles of care for children

with disabilities into training programs for health professionals and parents

Medical information network (MINET)

Model standards

Regionalized systems of care

SPANS Grant (Special Projects of Regional & National Significance

Supporting research in care of children with disabilities

The 4 mysteries – the human infant, parenthood, personal courage, and family love

Ventilator-dependent children

American Medical Association

Governor Bond

Crippled Children's Program at the University of Illinois

John F. Kennedy Institute (Baltimore)

The American Academy of Pediatrics

The American Coalition of Citizens with Disabilities

The American Association of Mental Deficiency

The American Association of University-Affiliated Programs

The Association for Retarded Citizens - US

The Association for the Severely Handicapped

The National Association of Children's Hospitals and Related Institutions

The National Downs Syndrome Congress

The Spina Bifida Association of America

University of California

University of Iowa

University of Michigan

University of Pennsylvania

University of South Carolina

Vanderbilt University